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Changing Choices: Disabled and Chronically Ill People's Experiences of Reconsidering Choices

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Abstract

Objectives

To increase understanding of disabled and chronically ill people's experiences of revisiting choices by considering events that prompted people to reconsider choices; what factors motivated them to act upon these events; and what factors affected their experiences of revisiting choices.

Methods

A sub-sample of 20 disabled and chronically ill people who took part in a qualitative, longitudinal study exploring choice-making in the context of changing circumstances. Each person was interviewed three times. Analysis focussed on choices that people had been prompted to revisit.

Results

Most choices were about health or social care and were revisited within a year due to: changes in health or social circumstances; poorer than expected outcomes; and external interventions. People were motivated to make changes by a desire to maintain independence and control, but perceived short term costs of decision-making could act as a deterrent. Experiences of revisiting choices were affected by help from other people and emotional strength.

Discussion

Making and revisiting choices is complex; people need support to engage with the continual cycle of choice-making. People who instigate revisions of their own accord may be particularly vulnerable to lack of support.

Keywords

Choices; revisiting choices; disabled people; experiences; qualitative research

Introduction

This paper uses data from a sub-sample of participants in the Choice and Change project – a longitudinal, qualitative study of choice-making over time – to explore the experiences of disabled and chronically ill people who go back and reconsider choices they have made about their health, social care and other service-related support.

Making and reconsidering choices is not unique to disabled people. Everyone makes choices every day, typically considering two or more options and choosing the one which is expected to offer most benefit. When events occur or new options arise that might alter these benefits (for better or worse), people are likely to revisit the option they have chosen to see if it is still the most beneficial or whether an alternative might be preferred. These choice cycles are continuous with multiple revisions being made and multiple cycles ongoing at any one time.

While it is not unusual to make choices and then revisit them when circumstances change, the lives of disabled people and those living with chronic illnesses can be characterised by changing circumstances; even when symptoms are stable, changes in other circumstances, such as housing arrangements or the availability of informal support, may necessitate new choices about support arrangements.¹ These characteristics mean that disabled people are likely to face not only many choices, but

many choices that subsequently need revisiting. Little is known about how welfare-related choices relating to, for example, health and social care or housing, are shaped over time; in particular there is little understanding of the frequency with which choices about welfare-related services need revisiting or the impact that revisiting them has on disabled people.

This is an important gap in knowledge, especially in the current policy context in which choice is central to consumerist policies in many countries, including the UK, other European countries and Australia.² Key to these policies (in social care in particular), has been the development of budgets (cash or virtual) that aim to give individuals the chance to exercise greater choice and control over the way their needs are met. In England, the promotion of cash budgets known as direct payments as a means of facilitating choice is particularly strong in social care.³

While there is a plethora of evidence from experimental psychology and economics about decision making (see Beresford and Sloper⁴ for a review), empirical research about the experiences of people who revisit and subsequently change their choices is scarce. Policy debates and associated research have tended to focus instead on the evaluation of choice at a higher level, assessing it against outcomes such as equity, efficiency, quality or public involvement.⁵⁻⁹

Increasing our level of knowledge about individual experiences is essential if we are to gain a greater understanding of the interactions between real life situations such as pain, uncertain illness trajectories, well-being, and choice-making. Empirical evidence to date suggests that people can find the process of making choices difficult due to an overwhelmingly large range of options from which to choose.^{10, 11} Older people have been shown to be more likely to avoid making choices^{12, 13} while repeated choices may be less demanding than making new choices as existing experiences and information can be drawn upon.¹¹ While these findings are relevant to the current study, they are not specific to disabled people or those with chronic illnesses.

What is known is that disabled people can find accessing appropriate information to help make choices particularly difficult and that emotions play a central role.¹⁴ In addition, there is evidence that some of the practicalities of making choices, such as moving between geographical or service boundaries, might lead to discontinuity of services¹⁵ or inequalities in the services provided to individuals.¹⁶ Even so, there is still little evidence about how revisiting choices is experienced by disabled people.

This paper aims to help fill this gap by increasing our understanding of disabled people's experiences of revisiting choices they had made previously. Specifically, it considers what events prompted people to go back and think again about choices; what

factors motivated them to act upon these events; and what factors affected their experiences of revisiting choices.

Methods and sample

This paper draws on findings from a sub-sample of 20 disabled and chronically ill people (both working age and older) who took part in the Choice and Change project - a qualitative, longitudinal study exploring choice-making in the context of changing circumstances. Multi-centre research ethics approval for the study was obtained.

Participants were recruited from a wide range of organisations in England, including: condition-specific voluntary organisations and support groups; hospitals; local authority (LA) adult care services departments; minority ethnic community groups; an independent recruitment agency; and ‘snowballing’ from other study participants.

Potential participants were approached by managers or leaders of these organisations and asked to post an ‘expression of interest’ form including their contacts details to the study team if they would like to take part or wanted further information. A member of the study team then telephoned the potential participant and, if they met the selection criteria of having support needs (see Box 1) and were willing to take part, gained verbal consent. Written informed consent was obtained at the first interview.

All participants had support needs; they were selected purposively to include people with support needs that were long-standing and fluctuating, meaning that additional services might be needed on a temporary basis; and those with the recent, sudden onset of support needs resulting from an accident or sudden deterioration in health (see Box 1). The main conditions represented in the sample were: chronic obstructive pulmonary disease including chronic bronchitis and emphysema; various forms of arthritis; neurological conditions such as multiple sclerosis and stroke; physical conditions such as amputation or spinal injury; and digestive disorders such as Crohn's disease. The range of conditions included was kept deliberately broad to ensure a focus on support needs of disabled and chronically ill people generally rather than those associated with specific conditions. The purpose was to create a sample that included people accustomed to making welfare-related choices as well as those relatively new to making such choices. Box 1 shows the pre-defined sampling quota used to ensure diversity in age, gender, ethnicity and living arrangements.

Fifty two disabled people were recruited to the study. Each participant was interviewed three times between 2007 and 2010. Participants were asked in each interview to discuss in detail a recent important choice they had made, including the options and information available, the roles of other people in making the choice, and the outcomes of the choice. In the second and third interviews participants also reflected back on the

choices discussed in earlier interviews. A wide range of choices was discussed, including choices about health care; social care, such as help at home and user-held cash direct payments (DPs) used to purchase support; minor and major housing adaptations; and support for employment. Interviews were recorded and transcribed in full.

After each interview, researchers created a 'timeline' for each participant that summarised the main changes, new choices and adaptations to previous choices that had been discussed. Over the period of the three interviews, these timelines helped build a picture of people's lives.

The research team focused analysis around pre-determined areas of interest (such as the role of information in making choices, the roles of family and friends, the options available, and the outcomes of choices). Subsamples of transcripts were also read by at least two members of the team to identify other emergent themes and finalise a framework for analysis.¹⁷ All transcripts were then read and coded with the aid of the computer-assisted qualitative data analysis software MAXqda, and summarised in a series of charts, following the Framework approach.¹⁸ This approach is a method of analysing data through creating tables (known as charts). Each chart covers a theme of interest, with each row representing a participant and each column a specific aspect of a

theme. Each cell contains a summary of relevant data. This method of displaying the data aids identification of more/less common issues, within and across sub-groups.

Twenty participants who spoke in detail about their experiences of re-considering earlier choices were identified from the timelines. Data from these 20 participants were analysed for this paper. Table 1 gives the characteristics of these 20 compared to the 52 in the main study.

The nature and timing of the interviews meant that although they took place annually over a two to three year period, they were nevertheless snapshots of people's lives at what was effectively a random time in their lives.¹⁹ Thus, while in many cases the data on changes in circumstances and revising choices spanned two or three interviews, in some cases the data were extracted from a single interview. The charts drawn up for this paper were therefore anchored around a choice and subsequent changes to that choice, irrespective of when these events occurred during the fieldwork period.^{20, 21}

Findings

Table 2 summarises the choices discussed by this sub-sample of 20 participants. Two participants discussed revisiting two choices; thus the number of choices discussed is 22. The table illustrates the wide range of participant characteristics and conditions as

well as giving brief summaries of the original choices made, the main events that prompted people to revisit those choices, the time elapsed between the original choice and the trigger event, and the revised choice made (if any). The issues surrounding the choices are discussed in more detail in the text. Once all 22 choices had been analysed, no new themes were emerging which suggests saturation was achieved.

Almost half (10/22) of the revisited choices involved social care and a further six revolved around health care. The remaining six revisited choices were about housing, employment, aids and adaptations, and transport and leisure. The length of time elapsed between the original choice being made and it subsequently being revisited ranged from less than a month to around 10 years. Typically, a choice was in place for a year or less before an event occurred that prompted it being revisited (12/22 choices); in an additional seven cases the period of time was two years or less. This illustrates how frequently disabled people are re-assessing their options.

Trigger events

People were generally prompted into reconsidering their choices by a 'trigger event'. The main types of trigger events were: changes in health or social circumstances; poorer than expected outcomes; and interventions by external organisations or professionals.

It is interesting to note that these events sometimes arose of the person's own accord (for example, through a desire for a change in lifestyle), but were sometimes events outside people's control (for example, the ill-health of a care-giver or an assessment by a professional). Thus, some people reconsidered their choices voluntarily and others compulsorily.

Changes in health or social circumstances

Changes in health could be sudden or gradual. Sudden changes included those that necessitated emergency admissions to hospital or immediate contact with health care professionals. More gradual changes, usually deteriorations in mobility, led people to question their ability to cope with current levels of support. An example is a mother who had MS. Over time, as her physical impairments increased, she reconsidered her choices about care, from coping alone to receiving home care services, then to arranging this herself through direct payments, and finally to getting help from social services to manage the direct payments (#4). Not all changes in health involved deteriorations; improvements could mean people were able to consider reducing their current level of support or perhaps take more major life course decisions such as moving house.

Changes in social circumstances also prompted revisions. Typically, these changes involved the availability of carers, both formal and informal. For example, moving

house or moving away from informal carers necessitated reconsidering the level of formal care provided; illness of informal carers prompted similar considerations.

Unusually, a mother reconsidered the timing of the steroids she received to help manage her MS (#12). She had received the steroids at the most clinically appropriate time, but questioned this choice of timing when the clinically appropriate time and the time she wanted to feel at her best (for her son's graduation) did not coincide.

Poorer than expected outcomes

Poorer than expected outcomes prompted people to reconsider their choices even where health or social care circumstances had not changed. For example, a working age woman with Crohn's disease had been determined to find and adapt to the optimum dose of an auto-immune drug but, after a year of trying, decided that she would return to other methods of managing her condition (#11). Similarly, older people with chronic illnesses were prompted by the unreliability of their home care services into reconsidering their need for these services (#7, #8).

Interventions by external organisations or professionals

Some interventions by external organisations and professionals in effect forced people into reconsidering their choices. These interventions took the form of audits or other routine assessments. For instance, a working age man with a fluctuating but

deteriorating condition had had an extension and adaptations made to his family home (#17). Upon completion, a local authority occupational therapist discovered through a routine assessment that many of the adaptations were inappropriate for his needs and thus she requested that he alter them. In another case, a social worker queried the legality of a working age woman's use of direct payments for horse riding; this meant the woman had to prove this use met her care needs or stop using the funds in this way (#1).

Underlying motivations

Further analysis of the data showed that, despite the more obvious trigger events that led to people reconsidering their choices, the underlying motivation that resulted in people reacting to these events was a desire to maintain the benefits from these choices. Within this general desire for the best possible benefits, people prioritised independence and control. Many people felt that trigger events were a threat to their physical or emotional independence. People with chronic and deteriorating illnesses had often fought hard to maintain as much independence as possible and were concerned when this was under threat. This concern is illustrated by a mother with MS who revisited her choices about care at home as her condition deteriorated; although the trigger event was a physical deterioration, underlying this was a determination to maintain her emotional independence and control over her life and that of her family:

My fear was losing control over my life. My fear was people coming into my home and telling me what I need. People coming in and trying to tell me what I need, what my kids need ... (#4)

Similarly, an older woman who had opted previously to remain at home when ill rather than be admitted to hospital was forced into reconsidering this choice during a serious illness. The trigger was a change in her illness but independence and control were at the core of her decision:

... [home's] where you still have the control and you still have some independence .. and that's vitally important. (#14)

The timing of benefits also emerged as an important issue. The woman who changed the timing of her steroid treatment to fit better with her social life realised through this event that she was empowered to take more control over her treatment and therefore create opportunities to be more involved in family life.

...it's about actually saying "It's my body and, yes, I would like it [steroid treatment] now" [...] I want to be alright while [sons] are young enough to

want me a bit, you know, I want to be able to do a few things with them.

(#12)

Not only did people aim to maintain maximum benefits from a particular choice, their wider lifestyle preferences also motivated them to revisit choices. Thus it was that two working age women considered moving to different parts of the country – one because she wished to study elsewhere (#2) and the other because she wished to fulfil a dream to live in a remote area while she still felt physically capable of doing so (#3). For both women, it was the combination of the underlying desire to make these lifestyle changes and the external trigger of better health and support which lead them to realise that the time was right to instigate change:

I mean that, that is part of my reason why I want to go because, you know, I'm not getting, I'm probably worse than I was in, in the way that me muscles are sort of breaking down a bit and so on, but if.. if I don't go in the next couple of years I'm going to get poorly, my dad is going to get even more dependent on my mother and the rest of us, my mum's going to be more dependent on us. If I don't go, by the time my dad's died, which is a really sort of sorrowful thing to say, I'm going to be too ill to go. (#3)

For some, however, the short term effort involved in revisiting a choice could be demotivating. This was usually the case when people felt that they had invested significant time and energy into making a choice only to discover that the benefits were not as positive as expected. In these situations people were unlikely to make substantial changes. They used phrases such as “*can I be bothered?*”, and feeling “*noticeably weaker*” or “*weary*” to describe the general fatigue they felt; this was not just general tiredness but being tired of constant change. One man with MS made the decision not to go on holiday again after a poor experience coping with unsuitable accommodation:

...the experience of that has sort of like made me decide that I'm not going to bother to try and go on holiday again. Cos of the .. the effort. (#17)

People were also wary of the uncertain consequences of modifying choices; this uncertainty meant people found it easier to stick with the status quo even though they were aware that by modifying their choices they might be able to improve their long term well-being.

Where people opted not to revise choices, the short-term costs (non-financial as well as financial) weighed more heavily in their decisions than potential long-term benefits. However, it could be argued that these were optimum and rational decisions, at least in

the short-term; that is, people had made a judgement that the effort of revising the choice outweighed the potential gains. But the question arises: with appropriate support, would people have revised their choices and increased their long-term well-being?

Factors affecting people's experiences of revising choices

The data showed that once people had decided to revisit choices, three main factors affected their experiences: help from friends and family; help from professionals; and emotional strength.

Help from other people appeared to be crucial. Where people felt weary with the effort involved in making and implementing choices, family and friends might step in and help out: *"I've also got [partner] who makes my phone calls when I'm too tired.. [...] so she's able to sort of go in and fight when I'm saying "I don't want to"."* (#2). Living alone did not appear to be an impediment to feeling supported. However, lack of communication could mean that, although help was available, it did not materialise. A woman whose husband (who was also her carer) was admitted to hospital realised, months after her struggle to cope alone, that his family had been willing to help but had not offered because of concerns about being seen as interfering (#5). Lack of family

support more generally was rarely mentioned but where it was missing it impacted negatively on people's experiences of reconsidering choices:

There are some people who, you know, are supportive of their partners who have MS [...] there are lots of others .. that .. can't handle it. They just, they just, it's not what they signed up for and they don't want it. (#17).

Help from professionals was cited as a key factor in feeling empowered in revising choices. Help could be quite general, such as showing understanding of a person's decision to revise a choice; this strengthened people's resolve and could be perceived as endorsing decisions to revise choices, as illustrated by the following quote in which a woman was revisiting her choice about asking for help at home:

...the social worker was influential, because the social worker kind of gave me permission, emotionally she gave me permission to allow somebody else to take care of me... (#5)

Alternatively, support might be more specific, for example, a nurse showing someone how to inject themselves; specific actions such as this in effect created new options by increasing people's confidence and skills. Participants also felt that unconventional

options could be legitimised by professional support and willingness to bend the rules. Conversely, pressure from professionals who disagreed with choices or had strong views about which course of action to take was considered unhelpful and disempowering; such pressure encouraged a focus on a limited range of options.

Another important factor that helped in decisions about revising choices was people's own emotional strength. Those who felt positive and emotionally settled with their lives (irrespective of changes in health or social circumstances) appeared to have the necessary impetus to begin to implement change. Emotional strength included being confident enough to challenge authority. For example, one woman (#1) was successful in retaining her preferred option of using direct payments for horse riding; another was successful in challenging her consultant over the timing of her steroid treatment (#12). Determination also helped people to learn new skills that expanded the options available. However, determination not to fail could also lead to delays in revising choices; a man who was using a hoist at home was so determined "*not to be beaten*" by it, and not to make transfers more difficult for his carers, that he used the hoist for longer than necessary (#19). In effect, he had better alternatives available but delayed the decision to use them.

Other factors that affected people's experiences of revising choices were bureaucracy and rules; these were seen as hampering efforts to revise choices rather than supporting them. They created particular difficulties in relation to direct payments. One woman was put off a move to a different council area by uncertainty about the rules (#3) and another made minor changes without notifying the council (#4). People learnt that rules might artificially limit available options but, with emotional strength and determination, they could be challenged and potentially changed.

Discussion

Summary and discussion of main findings

This paper has explored the circumstances that prompted disabled and chronically ill people to reconsider choices made previously, and their experiences of doing so. The study was based on a small sample of disabled and chronically ill people in England, but the insights provided are likely to be recognised by and of interest to people with long term conditions more generally, as well as professionals in health and social care.

The findings provide important research evidence to help fill the gap in knowledge about the frequency with which disabled and chronically ill people make choices about welfare services. Choices in this study were typically revisited within a year and almost always within two years. Some people revisited their choices voluntarily after

improvements in health or decisions to implement lifestyle changes, but others were forced involuntarily into revisiting choices after sudden deteriorations in health or assessments by professionals. Although the study did not continue long enough to follow people through a number of these sequences, it is likely that this pattern of events continued in the longer term. It is also likely, based on findings from analysis of an associated dataset, that multiple choices are being considered at any point in time;²² the lives of the participants are thus more complex than presented here.

In the majority of cases considered, choices were revisited in the expectation that they could be altered in some way that improved well-being, especially independence and control. The prioritising of independence and control in decision-making is consistent with other findings from this study²³ as well as the more general philosophy behind personalisation of support.^{24, 25}

There were two types of exceptions. First, people might revisit their choice with the explicit intention of not revising it; this was usually where an external event had triggered a response in a situation where people were otherwise content. These people were, in effect, being forced into justifying their current options. Second, some people understood that their long-term well-being might be improved by changing their choice, but chose not to make that change because of excessive short-term costs. The reasons

for taking a short term view included fatigue with decision making, uncertainty and lack of support; these have been shown previously to be difficulties associated with decisions relating to cash direct payments.^{15, 26} This ‘myopic view’ in decision making is confirmed in different contexts by Langer and Weber²⁷ and Le Grand;²⁸ they consider risky investments and social exclusion respectively. The principle, however, remains the same: taking a short term view of costs and benefits associated with a potentially long term choice can result in a less than optimal decision. The findings in this paper appear to be the first presentation of empirical research evidence that myopic decision making occurs in welfare-related choices by disabled and chronically ill people. The implication is that if issues such as decision fatigue and lack of support can be addressed, disabled and chronically ill people may be helped in taking a longer term perspective when revising choices and thus, potentially, they may be able to increase their opportunities for enhancing quality of life.

The findings suggest also that people who are determined and self-confident, are not feeling too tired or ill, have support from professionals and family, and who feel able to challenge bureaucracy and seek information, will be well placed to seek alternative options and implement revisions that are expected to increase beneficial outcomes. However, people who lack some or all of these attributes might find it more difficult to adapt their choices to changing circumstances and thus be less able to maximise their

well-being. It is interesting, however, that there was no indication from this study that people found the range of available options overwhelming, as suggested by Schwartz¹⁰ and Tanius;¹¹ on the contrary, people were more likely to be concerned about the limited information they had about different options. The need for appropriate and accessible information and support for decision making by disabled and non-disabled people is not new^{14, 29} but remains an unresolved issue.

Strengths and the limitations

One of the main strengths of this research is that it is the first empirical research in England to explore the processes for disabled and chronically ill people of making revisions to welfare service-related choices. It has taken a longitudinal view, capturing participants' accounts of their choices, changes to circumstances and revisions to choices over a number of years. This has enabled the analysis to include participants' reflections back on their experiences as well as their reports of recent events. By asking participants to discuss choices that were most important to them, the data have been shaped by the issues of most importance to disabled and chronically ill people.

However, there are also limitations. Despite over 50 disabled people of working age or older taking part in the study, only 22 revisions to choices were discussed in sufficient detail for analysis. People in this study were asked to talk about a choice that was most

important to them, rather than to talk in detail about choices they had revisited; had they been asked the latter question, the number of choices revisited would perhaps be far greater. A further limitation is that the number of people with certain characteristics that might be of interest, such as over 65 year olds, people from minority ethnic groups and people with dependent children, was insufficient to show any differences in the ways that they experienced revisiting choices. In addition, the range of conditions and level of support needs was deliberately broad-ranging; whilst 22 choices is sufficient to give a good insight into people's experiences, future studies exploring these issues might consider longer follow-up periods or a focus on a particular subset of people, condition groups or types of choices.

Policy and practice implications

It is clear that personalisation will remain at the forefront of policy; in the UK in particular the responsibility for making choices and managing budgets continues to be devolved to the level of individual service users across a range of welfare¹⁶ and potentially health³⁰ services. Devolution of responsibility and control has been driven by disabled people and undoubtedly brings many positive benefits,^{1, 24, 25} however, devolved responsibility should not be confused with sole responsibility; people will continue to benefit from help from professionals and others in making choices. The findings presented here have illustrated the complex nature of choices and shown how

people can become fatigued with the continual cycle of choice-making that changing circumstances necessitate. The need by many people for support when revisiting choices is clear. This need is perhaps greatest for people who, for whatever reason, are less able to fight to retain their preferred option or to see beyond the short-term costs associated with changing their choices. Recognition at both the policy and practice level of the importance of help to engage with the continual cycle of choice-making is therefore essential.

Knowing when and with whom to engage, however, is complicated. This research has shown the types of events that trigger reconsiderations and revisions to choices. While some of these events, such as changes in health, automatically attract the attention of relevant professionals who can offer help and provide relevant information, others such as changes to social or personal circumstances do not. People who instigate revisions to choices of their own accord (for example, lifestyle changes after improvements in health) may be particularly vulnerable to a lack of support, especially if the time elapsing between the original choice and its revision is lengthy, making any previously available professional support and information inaccessible or no longer relevant. These people and others who have little contact with statutory or other organisations may be especially at risk of isolation when revisiting choices.

To conclude, an important new finding from this analysis is that some choices are revisited on a voluntary basis and some are obligatory. This has important implications for practice. As information-givers, professionals' roles are essential in aiding people to recognise and realise the range of options available. Obtaining this help and gathering appropriate information is likely to become more complex as increasing policy emphasis on local and community-run enterprises further diversifies the market for the provision of social and other welfare services, including sources of information and advice. Where there is little routine contact with professionals or other experts, the full range of options available may not be evident or may take substantial effort on the part of the service user to identify; this paper has confirmed that substantial short-term costs can deter people from changing their choices. A specific group of people who have little contact with professionals is that group who are self-funders. This group of people is likely to be making choices about social care, housing, leisure and transport rather than health care, however, with the increasing numbers of people using some form of personal budget in social care in the UK and increasing thresholds of eligibility for local authority-funded social care, the proportion of people making choices that are akin to self-funded choices will rise markedly. Although by no means universal, there are examples presented in this paper where it appears that more information may have resulted in more informed choices by people funding their own support. If self-funders do seek different forms or quantities of advice, questions remain about whether they are

less well informed about their options than people who have easy access to professional support, and what this means for the future in which more people will be managing their own budgets?

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Box 1: Criteria for selection and pre-defined sampling quota

Criteria for selection

All study participants had support needs. Support needs were defined as needing help with daily living activities (such as housework, shopping) and/or personal care (such as washing, bathing). Participants may or may not have been using statutory social care services at the time of recruitment and may have had cognitive and/or communication impairments.

Definition of long-standing, fluctuating support needs

- Significant levels of support needed at least part of the time;
- Level of support needs is intermittent and perhaps unpredictable; and
- Changes in need may necessitate regular re-appraisals of both current support arrangements and longer-term plans.

Definition of recent, sudden onset of support needs

- Health has recently deteriorated dramatically and rapidly; or
- The recent and sudden onset of a severely disabling condition.

Pre-defined sampling quota

The pre-defined sampling quota aimed to ensure diversity within the sample. We aimed to recruit approximately 25 participants with fluctuating support needs and 25 with the sudden onset of support needs. Within each of these two groups, we aimed for:

- About half the group aged under 65 years and half 65 years or older
- At least ten men in each group;
- At least eight people in each group with the following characteristics:
 - were from minority ethnic backgrounds;
 - had educational qualifications at A-level or above;
 - lived in rural or semi-rural localities;
 - had dependent children living at home;
 - lived alone.

Table 1: Characteristics of whole study sample compared to sub-sample that revised choices

Characteristic	Whole study sample (n=52)	Sub-sample (n=20)
Age 25 to 64	33	13
Age 65+	19	7
Fluctuating needs	30	12
Sudden onset of needs	22	8
Male	21	5
Black or minority ethnicity	7	3
Lives with dependent children	13	7
Lives alone	12	4

Table 2: Summary of participants' characteristics and revisited choices

Participant ID	Age Gender Main condition Support needs	Original choice	Trigger event that prompted revisit	Time elapsed since original choice	Revised choice
#1	<65 F MS Fluctuating needs	Social care – to pay for horse riding lessons from DPs	Audit by social worker	1 year	Not revised
#2	<65 F Fibromyalgia Recent onset of needs	Social care – to start using DPs	Desired move to different LA area	<2 years since began to use DPs	Home LA paid DP temporarily in different LA area
#3	<65 F Undiagnosed – joint damage, MS-like symptoms Fluctuating needs	Social care – to start using DPs	Health improvement Better control over support with DPs Desired move to different area	<2 years since began to use DPs	Participant considering relocation and portability of DPs when study ended

#4 (1)	<65 F MS Fluctuating needs	Social care –to start getting help from home care workers, but not to use DPs	Lack of control over home care workers	<2 year	Began to use DPs
#4 (2)*		Social care – to start using DPs and manage the administration herself	Health deterioration	<2 years	LA took over administration
#5	<65 F Fibromyalgia Recent onset of needs	Social care – to be cared for by husband rather than home care workers	Husband became ill	<1 year	Used home care agency temporarily, but poor quality experience
#6	>65 F Osteoarthritis and polymyalgia rheumatic Fluctuating needs	Social care – to be cared for by daughters (in addition to DPs)	One daughter became ill	<6 months	Requested increase in DP for home care - refused
#7	>65	Social care – to start getting help from	Poor quality experience	<6 months	Stopped care workers

	F Rheumatoid arthritis Recent onset of needs	home care workers			and coped alone
#8	>65 M Stroke Recent onset of needs	Social care – to start getting help from home care workers	Poor quality experience	<1 year	Stopped care workers and coped with wife's help
#9	>65 F Stroke Recent onset of needs	Social care – to start using meals on wheels service	Poor quality experience	<1 year	Stopped meals on wheels and coped alone
#10	<65 F Adult onset Still's	Health care – to start drug treatment	Adverse reaction to drugs	<2 years	Changed to self- injected drugs

	disease, scoliosis since childhood Fluctuating needs				
#11	<65 F Crohn's disease and fibromyalgia Fluctuating needs	Health care – to start drug treatment	Multiple hospitalisations	1 year	Stopped using drugs
#12	<65 F MS Fluctuating needs	Health care – to use steroids at time doctors suggested	Timing of son's graduation	1 year	Changed timing of steroids
#13	<65 F Stroke Recent onset of needs	Health care –to be admitted only to preferred hospital	Health improvement Poor quality experience	1 year	Opted to avoid all hospital admissions
#14	>65	Health care –to be admitted only to	Health deterioration	10 years	Opted to avoid all

	M Chronic bronchiectasis and asthma Fluctuating needs	preferred hospital	Poor quality experience		hospital admissions
#15	>65 F Chronic obstructive pulmonary disease Fluctuating needs	Health care –to avoid hospital admissions	Health deterioration	2 years	Not revised
#16	<65 F MS Fluctuating needs	Housing – to adapt bathroom	Health deterioration	3 years	Opted for only minimal revisions
#17 (1)	<65 M MS	Housing – to extend house and adapt kitchen and bathroom	Assessment by OT	<3 years	Opted for only minimal revisions

	Fluctuating needs				
#17 (2)		Leisure – to go on holiday to adapted caravan	Poor quality experience	<1 year	Stopped going on holiday
#18	<65 F Crohn's disease Fluctuating needs	Employment –to return to work	Health deterioration	<2 years	Reduced hours
#19	>65 M Stroke Recent onset of needs	Aids and adaptations – to use a hoist at home	Health improvement Poor quality experience	<1 year	Stopped using hoist
#20	<65 M Spinal cord injury Recent onset of needs	Transport – to buy first adapted car	Physically inappropriate car design	<1 month	Chose different design

F – female; M – male; MS – Multiple sclerosis; LA - Local authority; DP - Direct payment